

Commissioner's Message

Last fall, in the months following hurricanes Katrina and Rita, the DD Network response was overwhelming. Grantees in the affected regions worked around the clock to meet the needs of individuals with disabilities and their families. Grantees from across the Nation sent resources, money, and staff to assist their colleagues on the Gulf Coast.

It's hurricane season again. As our colleagues on the Gulf Coast continue to help families repair their lives and brace for the possibility of another storm, newspapers across the country are peppered with headlines warning of other potential dangers ranging from avian flu to terrorism threats. It is essential, then, that we as a Network work together to take the steps that will allow us to respond to an emergency not with panic, but with confidence and compassion. We must prepare for these potential disasters not out of fear or pessimism, but out of a desire that our collective reaction to unforeseen or unfortunate events will be both purposeful and effective.

Many lessons were learned in the months following Hurricanes Katrina and Rita. Perhaps most important among these lessons is that it is absolutely essential that we as a community of disability advocates form relationship with Federal, State, local and private emergency management stakeholders. In the event of an emergency, it is crucial that we communicate effectively and work smoothly with public and private emergency response teams. This collaboration should not be put off until a disaster is upon us. It must begin now.

This issue of the ADD Update focuses on Emergency Management. In it, I hope to outline steps that can be taken to improve planning, communication, and preparation. More than that, I hope to encourage an ongoing conversation between grantees, as well as among grantees and Federal, State, and local stakeholders. As part of the effort to facilitate that conversation, ADD and HHS, together with the Department of Homeland Security, were proud to sponsor the *Working Conference on Emergency Management and Individuals with Disabilities and the Elderly* on June 28-30 in Washington, DC. All States and the District of Columbia were invited to designate individuals

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ADMINISTRATION ON DEVELOPMENTAL DISABILITIES

Administration on Children and Families
U.S. Department of Health and Human Services



from Departments, Offices or Task Forces related to Aging, Health, Homeland Security, Emergency Management, and Special Needs Populations to represent them at the conference. Additionally, an ADD Grantee representative was part of each of these delegations.

The conference addressed three phases of emergency management: planning, response, and recovery. Attendees heard from experts and participated in workgroups. I was overwhelmed by the hard work and dedication of the speakers, delegates, and attendees.

At the conference, many important subjects were broached, new relationships were formed, and ideas were discussed. Perhaps most importantly, the foundation was laid to enable members of the disability and emergency management communities to work together.

I am confident in the ability of ADD's grantees to build on this foundation, and to create practical plans and solutions that will allow the needs of Americans with disabilities to be met in the event of a disaster.

I hope that in continuing to work together, conference delegates and other stakeholders will keep in mind three important concepts that emerged at the conference:

1. People with experience working with the disability and aging communities *must* be involved in all phases of emergency management: planning, response, and recovery. Members of these communities themselves should be involved as well, and must have defined roles in shaping solutions.
2. Individuals and organizations involved in emergency management planning have to get to know one another. The time to build solid relationships with other organizations is before the waters start to rise. By starting *now* to get to know other organizations, we can become familiar with each other's operations, and discover ways that our services and planning techniques can complement each other.

Topics of the Emergency Management Conference included:

- Day 1: Estimating populations and the viability of registries.
- Day 2: Accessible transportation and communication.
- Day 3: Coordination and restoration of services.

The goals of the conference for State delegations were to:

- Connect representatives from homeland security, emergency management, special needs, aging and disability with each other,
- Have an opportunity to work together and lay out how to strengthen the capacity of their State to assist target populations in an emergency or disaster,
- Take their consensus-based ideas back to their Governors, and
- Work together for the adoption and implementation of these ideas statewide.

The goals for Federal agencies and national organizations:

Just as State delegations and Regional Groups will be working through how to address specific topics, meetings of federal and national groups each afternoon will allow us to work through how we will facilitate these activities by working together at the national level.

For more information and resources from the conference, please visit: <http://add-em-conf.com>

3. Resource mapping is crucial. Everyone should spend time on documenting the availability and location of the resources that will be needed in the event of a disaster- supplies, vehicles, housing. During Hurricane Katrina, there were hundreds of accessible buses located within a few hundred miles of the disaster area that went unused because responders didn't know where they were or how to get permission to use them. In order to have access to the resources needed in a disaster, we must know where those resources are and how to quickly access them when they are needed.

These steps, and the many other steps necessary to implement appropriate and effective emergency response plans, do not have to be the responsibility of any one agency. Only by working together and sharing resources, skills, and ideas can we ensure that the needs of all Americans will be met.

At the conference, I was unable due to time constraints to thank the many individuals and organizations who made the event a success, and who are already working hard to improve emergency management initiatives. In addition to the Department of Health and Human Services and the Department of Homeland Security, the conference was made possible by the Administration on Aging, the Office on Disability, the Family and Youth Services Bureau, the Children's Bureau, the Substance Abuse and Mental Health Services Administration, and the Social Security Administration. I owe a great deal of thanks to Daniel Sutherland of the U.S. Department of Homeland Security, who served as co-coordinator for this event. Among the many other individuals to whom I am thankful are Secretary Michael Chertoff, Deputy Secretary Alex Azar, David Paulison, Dr. Wade Horn, Dr. Margaret Gianinni, Josephina Carbonell, Robert Zitz, Elizabeth Davis, Jim Mason, Joe Forsha, and Joanne Barnes. I am also grateful to the many others whose participation made this conference possible. I look forward to continued cooperation as we work together on this important issue.

Editor's Note: Pages 13-15 of this issue of the ADD Update contain a detachable emergency preparedness checklist specifically designed for individuals with disabilities. Links to additional resources can be found on the last two pages.

Spotlight on Self Advocacy

Finding a Voice

For Mia Peterson, being a self-advocate has always been about finding her voice.

Mia is a member of the Board of Directors of the National Down Syndrome Society, where she acts as chairperson of the Self-Advocacy Advisory Board and edits a regular bulletin. She's also a full-time employee of the Iowa Protection and Advocacy System, and she writes the internal newsletter there as well.



As a writer and self-advocate, Mia is living happily in her home State and has found a forum in which to voice her beliefs and opinions, but her journey towards that point began almost ten years ago, when she was still in high school.

One of Mia's hobbies has always been writing stories. As a senior in high school, Mia attended a National Down Syndrome conference with her father. She had the opportunity to share her fiction with representatives of the Down Syndrome Congress, who then asked to publish some of her stories in a new newsletter. Shortly thereafter, Mia was asked to be co-editor of the newsletter.

When the founder of a Cincinnati, Ohio-based business called Capabilities Unlimited read Mia's stories, Mia was offered a job writing for a newsletter by and for people with disabilities. She was able to work from home in Iowa for a while, and then she was offered a part-time position in Ohio.

"I was nervous, but I decided to take that risk," says Mia of the move. "My family supported me, because they wanted me to have this chance to live my own life. I'm glad that they did. It was worth the risk. That was the beginning of my self-determination."

In Ohio, Mia wrote for the newsletter, and helped other self-advocates get training. "People need to speak for themselves, not let other people speak for them," she says.

The move to Ohio was a positive, life-changing experience for Mia, but it came with challenges as well. "When I moved, I had to learn a lot of things," she says. "I had to learn how to do things on my own, how to work in an office, how to find my own voice, how to give others a voice by advocacy training."

The challenges and the risk were definitely worth it, says Mia. Now living in Iowa again, she has been working for the P&A for seven months. She loves her job, and loves working with people. In her spare time, she enjoys swimming, running, walking with friends, and bike riding with her family. She continues to be active in self-advocacy and looks forward to whatever experiences and challenges are next.

“What Did You Do Before This?": A Different Road to Self-Advocacy

By Kathy Cargill-Willis, ADD Program Specialist

During my first couple of weeks at ADD, a colleague (I love that word because in one word it conveys professional equality and team membership) asked me, “What did you do before this?” It wasn’t a question to challenge my credentials; she was just curious. But the answer is complicated for me, and I suspect it is complicated for many people with disabilities. It took me several decades to realize that my qualifications, abilities, and disabilities were not likely going to fit a job position found in the classified pages in your average Sunday paper. But I have experience-- professional experience and experience worthy of compensation.

I also realized early that research and the written word were going to my best friends. Now, with the Internet, research is so easy and so, dare I say, accessible. After twenty years of gathering research for political candidates, I discovered that if you go in to a meeting or an interview armed with paper and an attitude of “look what I can do for you,” or “you need me to do this for you,” instead of trying to fit into a job description, you will be more successful. This especially worked in the world of politics and academia where hiring practices are looser. This attitude generally reaped a job or a contract eventually, and although I was not selected for the position advertised, sometimes the conditions of the contract were more lucrative and gave me more worthy experience.

In the three years before joining ADD, I accomplished three things, things that are very significant to my career. I held a contract with the Ohio Developmental Disabilities Council digesting lengthy reports from federal agencies and experts in the disability arena. This job allowed me to become very familiar with the priorities and current trends in the disability field, giving me the ability to access reliable scholars in the field, such as David Braddock or Charlie Lakin. Secondly, I published my first novel, which was very exciting. “Dreaming A Life” is a fictional comparison of the life of a twin with significant disabilities and her able-bodied sister. The book is available at my local bookstore in Ohio and on Amazon.com. The third opportunity came as I described above. I interviewed for a position at a small health education company. Although I was not selected for the position, the company wanted me to develop three modules on disability issues. Since I already had the research at my fingertips, the whole project took me much less time than the company expected; therefore, when dividing my compensation by the hour the rate of pay was significantly higher than the original position for which I applied.

As I write this article, I have been at ADD for almost two months. It has been exciting, exhilarating, and exhausting. Did you know that after you walk from the metro to the front door of the HHS building, you walk another block to my office inside the building? And people ask me if I want to go outside for lunch, two blocks here and two blocks there? Last Friday we had a fire drill or a fire incident, I am not sure which. There was not a clear procedure for me to exit the building: do I wait for someone to have time to pick me up in the elevator, or do I take the stairs and possibly get knocked over or impede others’ exiting? Another incident happened late Friday afternoon when my supervisor came into my office and said that she needed me and two other colleagues to copy,

collate and make 30 packets for a meeting Monday. I looked at her and said, “You really don’t want me to do that, but I would be happy to do labels or the agenda.” It would take me forever to collate and I would wrinkle everything. She said, “Oh I forgot,” which I took as a compliment. Like any other team, my colleagues and I need to discover our individual strengths, abilities and weaknesses. When working with people with disabilities the process may take a little longer.

The point of this article is that the experience of people with disabilities may be different and may be acquired differently, but it may be no less creditable. Even if a self-advocate does not have thirty years, or even one year as a civil servant, his or her experience may be very strong and comparable to the professional!

Collaboration in Georgia: Children’s Freedom Initiative

Don Faulk loves country music, fireworks, go-cart rides, and veggie tales videos. As of 2005, however, Don had been living in an institution for six years-- half of his young life. Fireworks and go-carts, along with other favorite family activities, were only available on Don’s occasional visits home. Music and videos were played in his room in a nursing home where most of the other residents were senior citizens. Don loved being outside, but did not often get the opportunity to go out. He spent his days lying in bed, or occasionally sitting in a chair in the nursing home hallway.

Don’s mother wanted to bring him home. However, she couldn’t afford the services that Don would need. The State would pay for Don’s nursing home care, but not for the supports that would allow him to receive the care he needed to live his life at home with his family.

ADD and its grantees are dedicated to the principle that children like Don should never have to spend their lives confined in institutions. In Georgia, where Don lives, the three grantees joined forces to create the *Children’s Freedom Initiative*. This initiative was formed to make sure that in the future no child in Georgia will have to live in an institution.

The mission of the initiative is centered on the belief that children like Don belong with loving families – not in facilities. Currently, it is estimated that 140 – 150 of Georgia’s children are living in nursing homes and state hospitals. The DD Network is taking steps to change that.

As part of the Children’s Freedom Initiative, the DD Network worked cooperatively to bring together a diverse group of stakeholders at a summit to “ensure that children who live in facilities are given the chance to live with permanent, loving families” and to “imagine a future where no child will live in an institution.” In order to add value to the summit, the DD Network hired national consultants who have successfully moved children into permanent homes in other states. The summit clarified and reinforced the following messages:

- *Children need and deserve permanent homes and communities;*
- *Serving children (and other persons) with disabilities in the community is much more cost-effective than serving them in institutions; and*
- *Every child can live in the community with the correct support system in place.*

During the 2005 legislative session of the General Assembly, House Resolution 633 was introduced to look into this issue. This resolution resulted in the creation of an oversight committee. The non-legislative members of the committee are persons with disabilities, family members, and representatives from the DD Network.

In conjunction with this project, the P&A and the Council jointly funded "Longing For Home", the powerful video/DVD about the initiative. In addition, UCEDD-affiliated graduate student Katie Bailey interviewed 6 families whose children were or are now institutionalized in Georgia and wrote stories for a publication called *From Loving Arms*. UCEDD staff disseminated over 1000 copies of this publication. A picture of Don Faulk was featured on the cover.

In August 2005, at the Children's Freedom Initiative Summit in Atlanta, Don's mother held a copy of *From Loving Arms* over her head and tearfully asked, "Why can't I bring my son home?"

During the most recent session of the Georgia legislature, funds were approved so that all of the children in Georgia's state-administered institutions can go home. Next year, the DD Network will work with the legislature to tackle the issue of children in private facilities & nursing homes.

With the help of the Children's Freedom Initiative and the P&A's advocacy efforts, Don at last went home to live with his family in February 2006. He has a swing in his backyard, and is receiving good support from his school.

"He's so happy," says Don's mother Laurie. "He's always giggling and trying to talk. Six years lying in bed and now he's just happy."

The purpose of this update is to provide current information about progress on the Independent Evaluation and current activities being implemented. This will be a regular feature of the ADD Update to ensure that you are knowledgeable about the Independent Evaluation processes and activities.

ADD Independent Evaluation Update

Westat has been hard at work and making progress on the ADD Independent Evaluation project. As we reported in the March ADD Update, Westat established **working groups** for each of the ADD grant programs (DD Councils, P&As, and UCEDDs), which are comprised of Executive or Associate Directors of the respective programs and a DD Council Chair. More recently, a collaboration working group was established by drawing from the three program workgroups. Below is a listing of the members of each working group:

P&A Working Group

Mary Faithfull, Texas
Sarah Wiggins-Mitchell, New Jersey
Robert Joondeph, Oregon
Timothy Shaw, Nebraska
Jeanne Thobro, Wyoming
Tom Gallagher, Indiana

DD Council Working Group

Jamie Wolfe, Delaware
Debra Dowds, Florida
Vendela Collins, Michigan
Becky Maddy Harker, Iowa
Richard Weathermon, Nevada
Waynette Cabral, Hawaii
Bill Lynch, Oregon

UCEDD Working Group

Lucille Zeph, Maine
Tawara Goode, Washington, DC
Fred Orelove, Virginia
Fred Palmer, Tennessee
David Mank, Indiana
Carl Calkins, Missouri
Gloria Krahn, Oregon

Collaboration Working Group

Fred Orlove (UCEDD), Virginia
Jeanne Thobro (P&A), Wyoming
Becky Maddy Harker (DD Council), Iowa
Robert Joondeph (P&A), Oregon
Bill Lynch (DD Council), Oregon
Gloria Krahn (UCEDD), Oregon

These working groups represent a range of program characteristics, including the geographic location, size, funding levels, and administrative home for the program.

The purpose of these working groups is to help Westat develop **DRAFT** performance standards for each program and for collaboration across the DD Network grantees. Evaluation in its most basic form is a simple comparison of “what is” to an expectation of “what should be.” The standard is what should be, and through the examination of new or existing data on what is, the evaluation process will determine the extent to which the program meets each standard for each program function. The working groups are helping to develop standards that will be designed around the characteristics of effective DD Network programs and collaboration among the three programs.

DRAFT performance standards are being developed for each program’s **key functions** as well as the **key functions** for Network collaboration. Although each of the three DD Network programs has the same long-term goals that emanate from the DD Act, each program functions differently to achieve those goals.

Currently, the working groups are hard at work assisting Westat in characterizing the key functions of each DD Network program. This process has included a series of meetings of each working group organized by Westat. All working groups have had one in-person meeting as well as several

conference calls. Members of the working groups have also conducted work off-line.

The meetings of the working groups have consisted of discussions of key concepts and issues, including the following:

- What are the key functions of the P&A/UCEDD/DD Council?
- What are the goals of each key function?
- What are the characteristics of a successful P&A/UCEDD/DD Council? j
- What are the characteristics of successful collaboration?
- By what standards does the P&A/UCEDD/DD Council measure its own success?
- How does one characterize and identify the impact of each DD Network program on:
 - The ability of individuals with developmental disabilities to make choices and exert control over the services, supports, and assistance they use;
 - The ability of individuals with developmental disabilities to access services, supports, and assistance in a manner that ensures that such an individual is free from abuse, neglect, sexual and financial exploitation, violation of legal and human rights, and the inappropriate use of restraints and seclusion; and
 - The extent to which DD Network programs collaborate with each other to achieve the purpose and principles of the DD Act?

Future discussions will address data requirements and measurement tools necessary to measure the indicators that are developed as well as discussions of existing data that can be used for this evaluation.

Westat hopes to complete discussions with the working groups by the end of August, 2006. Once this work is complete, Westat will organize the **DRAFT** performance standards for each key function into evaluation tools called **measurement matrices**. These **DRAFT** measurement matrices will be presented to **Validation Panels**.

Westat will establish four Validation Panels. The role of the Validation Panels is to review and comment on the contents of the **DRAFT** measurement matrices in order to achieve consensus on the matrices before they go forward for pilot testing. Panels will be comprised of DD network program staff and DD Council members, ADD staff, and others with expertise in issues facing the developmental disabilities community (e.g., self-advocates, family members, advocates) and evaluation research background. It is intended that the Validation Panels will be established in the summer of 2006 and will begin meeting in late summer or early fall.

As you can tell from this update, much has been accomplished over the past few months and there is much more work to be done in the coming months. ADD will continue to keep you informed on the Independent Evaluation project through the ADD Update. In the meantime, if you have questions about the activities being carried out through this project, please contact Jennifer Johnson at 202-690-5982 or jennifer.johnson@acf.hhs.gov.

Program Progress

Connecticut DD Network

The Connecticut DD Network has developed a *Guide for Including People with Disabilities in Disaster Preparedness Planning*. This guide, written for municipal and regional planners, reflects information, concerns and recommendations that emerged at the day long forum on December 6, 2005 on "Lessons Learned" from recent large scale disasters that affected states along the Gulf Coast. While the guide is intended to facilitate planning at the regional and local levels, it also contains information that will be useful to individuals with disabilities and their families, and identifies some critical issues that need further development at the systems level in Connecticut. The goal of the guide is to provide for people with disabilities at the same level of safety afforded to all, and to have people with disabilities involved in the process to plan, advocate, and take charge for themselves. ADD is pleased to offer a copy of this excellent tool to all attendees at the *Working Conference on Emergency Management and Individuals with Disabilities and the Elderly* on June 28-30 in Washington, DC. Additionally, the full text of the document is available at <http://www.ct.gov/opapd/cwp/view.asp?Q=316886&A=1782>.

Minnesota UCEDD

The National Association of State Directors of Developmental Disabilities Services (NASDDDS), in conjunction with the Research and Training Center/Institute on Community Integration at the University of Minnesota, is developing an emergency preparedness self-assessment instrument for state developmental disabilities agencies. The new self-assessment tool is being constructed to assist member state agency officials evaluate the extent to which their existing preparedness plans are able to address the unique characteristics of individuals receiving support through publicly funded developmental disabilities programs.

Katrina Aid Today

Katrina Aid Today is a national case management consortium of nine nonprofit partners, led by United Methodist Committee on Relief. One of the participating partners is the National Disability Rights Network, through which many P&As are participating in the relief effort. The program is facilitated by the Federal Emergency Management Agency of the Department of Homeland Security.

Under Katrina Aid Today, the Mission of NDRN is to provide high quality, cost-effective nationwide case management services for displaced individuals with disabilities and their families. Designed to support displaced individuals with disabilities and their families in regaining self-

sufficiency while building cohesive and inclusive communities, the Protection and Advocacy Network is:

- identifying individuals with disabilities and their families in this population and establishing mechanisms for them to contact P&A agencies;
- taking referrals of complex disability cases from other Consortium partners;
- assisting individuals and their families to develop individual recovery plans;
- supporting the implementation of these recovery plans by navigating through complex delivery systems related to disability and other human and social services, supports and accommodations; and
- Connecting these individuals with additional resources through the Consortium, as well as legal or other advocacy services in the community if necessary.

In order to meet the goals and objectives of KAT, NDRN created a two-tier system.

Tier I consists of nine, primary P&As in the states with the highest numbers of individuals affected by Hurricane Katrina – Louisiana, Texas, Mississippi, Alabama, Georgia, Florida, Tennessee, Illinois and Arkansas.

Tier II consists of low-incidence P&As standing ready to assist identified evacuees. They are Colorado, Indiana, Michigan, Missouri, New Jersey, New York, North Carolina, Ohio and Pennsylvania.

Program Performance

DDC and PADD Annual Reports:

In May 2006, ADD completed the process of reviewing and approving the DDC FY 2005, PADD FY2005 PPR, and PADD FY 2006 SGP reports. Currently, ADD and its Contractor are compiling and analyzing the data. Once ready, these national aggregate data will be used in the annual GPRA report, the FY 2008 Budget Requests and the data tables will be published on the ADD's Web site.

Five Year State Plan Reports:

In May 2006, the blank Five Year State Plan form was deployed on the ACF Online Data Collection (OLDC) platform. With this form on OLDC, ADD has all DDC and PADD reports available on OLDC.

DD Councils will be submitting their new five-year state plans (effective FY 2007-2012) on the OLDC for ADD review and approval on/by the due date -- Aug 15, 2006.

Contact Syed Rafiuddin @ srafiuddin@acf.hhs.gov for any technical issues and questions.

Announcements and Updates

Councils' Technical Assistance Institute

The Councils' Technical Assistance Institute, *Bolder Voices: Building Leaders and Telling Our Stories*, was held on June 5th and 6th in Baltimore, MD. The conference focused on finding new ways to tell the Councils' stories and effectively communicate their messages. Neil Romano, who is considered among the nation's leading authorities in the field of media and public advocacy, served as the keynote speaker. In 2003, Mr. Romano founded America's Strength Foundation, a private organization designed to help people with disabilities find main-stream employment. In addition, Mr. Romano owns The Romano Group, a multi-media production and consulting firm. In addition to his keynote address, Mr. Romano served as the lead speaker for two breakout sessions, and educated conference attendees on subjects such as shaping messages and handling public relations. Other sessions focused on data collection and other communication-related issues.

The P&A/CAP TASC Annual Conference for 2006

The Annual Conference for the Protection and Advocacy (P&A) systems and Client Assistance Programs (CAPs, for employment) was held June 13-16. It was sponsored by various federal programs, including the Administration on Developmental Disabilities (ADD), and was administered by the federally funded Training and Advocacy Support Center (TASC), a division of the National Disability Rights Network (NDRN). This conference covered a lot of topics and generated a lot of excitement.

The first day of the conference was focused on Training Institutes, which provided opportunities for specialized training in areas critical to P&A effectiveness. These included Secondary Investigations, non-litigation strategies for preserving Medicaid, communication strategies.

The plenary in the morning of the second day featured Eric Treat, a self-advocate, as the master of ceremonies, with panelists discussing "How Consumer Advocates Can Make a Difference," and the plenary in the morning of the third day focused on "Employment as Community Integration."

The main body of the conference, beginning on the second day, comprised seven training tracks, which were each focused on topics such as Community Living, Advocacy Strategies, Promoting Employment, Children's Issues, and Juvenile Justice issues. There were also, of course, tracks on Complex Legal Issues and on Abuse and Neglect issues. Self Advocates were highly visible at this conference, leading workshops such as developing voting materials for people with limited literacy and effective communications with individuals who are Deaf. There was also a workshop on working with the Hispanic and Latino communities, to help P&As improve their outreach. Helping people with disabilities to successfully participate in the voting process was well covered in this conference, including a review of the Rules Governing Election Advocacy and Election Protection Efforts. There was also a focus on the use of jails and prisons as a substitute for institutions, and the terrible abuses that occur in those settings

Emergency Preparedness Tips

The recent tragedies along the Gulf Coast highlighted the need to adequately prepare to meet the needs of Americans with disabilities during and after future emergencies. Moving forward, ADD's focus is not only on response to these hurricanes, but on ensuring that the lessons learned on the Gulf Coast this year will improve the services provided to Americans with disabilities in the event of future disasters.

After the hurricanes, ADD circulated an email to all grantees containing several tools that we hope will be helpful in developing emergency plans that address the unique needs of individuals with disabilities.

Attached to this email, grantees received the following documents:

- Disaster Preparedness for People with Special Needs and Persons Age 65 and Older Working Together When the Worst Happens: Nonprofit Emergency Preparedness in the National Capital Region
- FEMA: A Guide to the Disaster Declaration Process and Federal Disaster Assistance
- Disaster Solutions (compiled from various documents, including reports from ADD's grantees)

If you'd like a copy of the Disaster Solutions document, please contact Rebekah Yeager at ryeager@acf.hhs.gov. The other three documents, as well as other resources, can be found on ADD's website at <http://www.acf.hhs.gov/programs/add/resources/hurricanekatrina.html>. Additional links are provided in the last section of this newsletter.

The following checklist, compiled from FEMA and Red Cross recommendations, can be helpful in formulating disaster readiness plans for people with disabilities:

Emergency Preparedness for Individuals with Disabilities

Personal Support Network: A personal support network is made up of individuals who will check with you in an emergency to ensure you are O.K. and to give assistance if needed. Identify a minimum of three people at each location. Do not depend on any one person.

- ☐ Make arrangements, prior to an emergency, for your support network to immediately check on you (e.g., after a quake) and, if needed, offer assistance.
- ☐ Exchange important keys.
- ☐ Show where you keep emergency supplies.
- ☐ Share copies of your relevant emergency documents, evacuation plans, and emergency health information card.
- ☐ Agree and practice a communications system regarding how to contact each other in an emergency. Do not count on the telephone working.

- ☐ You and your personal support network should always notify each other to help each other in an emergency.

Emergency Contact List

- ☐ Ask several relatives or friends who live outside the immediate area (approx. 100 miles away) to act as a clearinghouse for information about you and your family (e.g., after a quake). It is often easier to place an out of state long distance call from a disaster area, then to call within the area. All family members should know to call the contact person to report their location and condition. Once contact is made, have the contact person relay messages to your other friends and relatives outside the disaster area.
- ☐ Besides emergency out-of-town contacts, the list should include emergency response agencies, personal support network, equipment vendors, doctors, utility companies, employers, schools, and day care center information for all household members. Post list by telephones.

Medications

- ☐ Work with your doctor to obtain an extra supply of medication, as well as extra copies of prescriptions. Make several copies of your prescriptions and put one copy in each of your survival kits, car kit, wallet, with your emergency documents and your evacuation plan.
- ☐ Ask your doctor if it would be safe to go without one dosage periodically, until an adequate supply has been accumulated.
- ☐ Ask your provider or pharmacist about the shelf life and storage temperature sensitivities of your medication. Ask how often you should rotate stored medication to ensure that the effectiveness of the medication does not weaken due to excess storage time.
- ☐ If you are on medications which are administered to you by a clinic or hospital (such as methadone, or chemo or radiation therapy) ask your provider how you should plan for a 3-14 day disruption.

Equipment and Assistive Devices

- ☐ Keep equipment and assistive devices in a consistent, convenient and secured place, so you can quickly and easily locate them during an emergency.
- ☐ Keep back-up equipment such as a spare battery or manual wheelchair.

Carry-On/Carry-With-You Supplies:

Supplies to keep with you at all times.

- ☐ Emergency Health Information Card that contains information about medications, equipment used, allergies and sensitivities, communication difficulties, preferred treatment, treatment-medical providers, and important contact people.
- ☐ Instructions on personal assistance needs and how best to provide them.
- ☐ Copy of emergency documents.
- ☐ Essential medications/copies of prescriptions (at least a week's supply)
- ☐ Flashlight on key ring.

- ☐ Signaling device (whistle, beeper, bell, screecher)
- ☐ Small battery operated radio and extra batteries

Supplies to Add to Emergency Kit:

Store in areas you anticipate will be easy to reach. If you have to leave something behind, make sure you get these.

- ☐ Food and water for 3 days (one gallon per person per day), blankets, non-electric can opener.
- ☐ Disability-related supplies for up to two weeks. (If unable to afford extra supplies consider contacting disability-specific organizations such as the Multiple Sclerosis Society, Arthritis Foundation.
- ☐ Life in cramped, unheated shelters can increase the chances of pneumonia and colds. Equip your kits with any vitamins or medications you take to guard against getting sick and to cope with being sick.

Communication: Practice Assertiveness Skills

- ☐ Take charge and practice how to quickly explain to people how to move your mobility aids or how to move you safely and rapidly. Be prepared to give clear, specific and concise instructions and directions to rescue personnel, i.e., “take my oxygen tank,” “take my insulin from the refrigerator,” “take my communication device from under the bed.” Practice giving these instructions with the least amount of words in the least amount of time.
- ☐ Be prepared to request an accommodation from disaster personnel. For example, if you are unable to wait in long lines for extended periods of time, practice clearly and concisely explaining why you cannot wait in line.

Conduct a Self-Assessment:

Evaluate your capabilities, limitations and needs, as well as your surroundings to determine what type of help you will need in an emergency.

- ☐ Have you designated a room in your home for shelter in case of a chemical or biological attack, and have on hand a roll of duct tape, scissors, and plastic to cover windows and vents in the room?
- ☐ Will you be able to shut off utilities (gas, water, electricity)?
- ☐ Can you operate a fire extinguisher? Will extended handles make this item available to you?
- ☐ Will you be able to carry your evacuation kit? Do you have duplicates at other sites?
- ☐ How will you evacuate? Move or secure large objects that might block your escape path.
- ☐ Write instructions for the following (keep a copy with you and share with support network)
 - . How to turn off utilities
 - . How to operate and safely move essential equipment
 - . How to safely transport you if need to be carried, and include any areas of vulnerability
 - . List personal care assistance needs (dressing, bathing etc.) with instructions on how best to assist you.
 - . Make a map of where to find medications, aids and supplies.

ADDED Resources

Emergency Preparedness is an ongoing process. Please check ADD's website frequently for updated links. www.acf.hhs.gov/programs/add.

Department of Homeland Security

- Disability Preparedness Resource Center: <http://www.disabilitypreparedness.gov/>
- Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities (ICC)
 - ICC Website
http://www.dhs.gov/dhspublic/interapp/editorial/editorial_0591.xml
 - 2005 Annual Report
http://www.dhs.gov/interweb/assetlibrary/CRCL_IWDEP_AnnualReport_2005.pdf
- FEMA Disability Preparedness Information
<http://www.disabilitypreparedness.gov/>

National Council on Disability

- *Saving Lives: Including People with Disabilities in Emergency Planning*
http://www.ncd.gov/newsroom/publications/2005/saving_lives.htm

Department of Justice

- *An ADA Guide for Local Governments: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities*
<http://www.usdoj.gov/crt/ada/emergencyprep.htm>
- *A Report on Special Needs Issues, Efforts and Lessons Learned*
<http://www.eadassociates.com/resources.html#gpub>

Emergency Preparedness Initiative of the National Organization on Disability

- *Emergency Preparedness Initiative Guide for Emergency Managers, Planners and Responders*
<http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureID=1034&redirected=1&CFID=6648848&CFTOKEN=70639594>
- *Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project*
<http://www.nod.org/index.cfm?fuseaction=page.viewPage&pageID=1430&nodeID=1&FeatureID=1588&redirected=1&CFID=6648848&CFTOKEN=70639594>

New York City Regional Office of Mental Retardation and Developmental Disabilities

- *911 Experience*
<http://www.eadassociates.com/resources.html#gpub>

IAEM Bulletins featuring Special Needs articles

- <http://www.eadassociates.com/resources.html#gpub>

The California State Independent Living Center

- *The Impact of 2003 Wildfires on People with Disabilities, April 1, 2004*
<http://www.eadassociates.com/resources.html#gpub>

Homeland Protection Professional – Special Needs Related Articles

- *Special People, Special Care, March 2006, by Lisa Gibney, Robyn Reese, Ned Wright*
http://add-em-conf.com/confdocs/special_people_special_care.pdf
- *Are We Prepared for the Cost of Preparedness, April 2006, by Elizabeth Davis*
http://add-em-conf.com/confdocs/Prepared_for_the_cost_of_preparedness.pdf
- *Special Products Section, April 2006*
http://add-em-conf.com/confdocs/Spec_Prod_Section.pdf

AARP

- *We Can Do Better: Lessons Learned for Protecting Older Persons in Disasters (Summary)*
http://add-em-conf.com/confdocs/AARP_summary-doing_better-seniors_and_disasters_2006.pdf
- *We Can Do Better: Lessons Learned for Protecting Older Persons in Disasters (Full Report)*
http://add-em-conf.com/confdocs/AARP_full_report-doing_better-seniors_and_disasters_2006.pdf

Tips For First Responders In Assisting Persons With Disability:

http://cdd.unm.edu/products/tips_web020205.pdf

We Want to Hear From You:

The next issue of the ADD Update will focus on cultural competence. Please send any suggestions, information, stories, and photographs to ryeager@acf.hhs.gov.